

Information from Healthwatch Sheffield - views received from carers in the last 12 months

- Problem with her child's role as a young carer - She doesn't feel that school are supporting her child adequately.
- Person is frustrated about cuts to social care services and the effects of cuts on individual budgets. Person feels fed up with the way carers are treated by the council. They received a letter just before Christmas saying their child's budget was being cut. They didn't think this was the best timing.
- Has a child with Autism and is unhappy with the services offered. They need support and help for them as they are the full time carer. HWS - signposted to Parent Carer Forum and Autism plus.
- Lady has cerebral palsy (& wheelchair user) and lives with a 24hr carer. Currently living in halls of residence in Sheffield (student at Sheffield Hallam). She had her care costs and rent for 24 hr carers paid by a neighbouring authority where she lived prior to university. She is having a problem with Sheffield City Council and the neighbouring authority who are both disputing who is responsible for paying for her care costs etc. HWS - booked face to face advice session with Sheffield CAB.
- Person is concerned that they feel there is no end of life care pathway for patients with dementia. These patients (like the person's Mother who died in December) have no access to at home palliative care in their final few months. GP services are unable to cope and are unavailable at evenings and weekends. Hospices won't take them. These patients and their carers find that there is nothing for them in these last few months. Mother died in pain at the weekend because of this. NHS 111 could only offer an ambulance to take Mum to hospital: a GP wasn't available quickly. She had a DNR precisely because we wanted to avoid the distress this would involve, but it should not have been a trade off between wanting her to die in her own home and dying in pain. Distressing experience trying to get help for my Mother as she was dying at the weekend. She died in pain and fear because no end of life pathway was available to her/us.
- Lady's mum has Alzheimer's - Adult Social Care were contacted about a care package assessment to be done last year. She wanted to know if she could get respite care for her mother as she was struggling to care for her full time. She felt that the adult services were appalling. When she rang she kept getting admin staff who said a social worker would contact her in a few days. She received no call from a social worker. She eventually received a care package assessment - a lady from an agency came to see her mum.

She was ok but it would have been good if she had been given 10 mins before the assessment meeting to prepare her mum (her mum did not know what was going on and was confused because of her Alzheimers). After the assessment interview they did not feel there was any way to contact the assessor if she had any questions about her mum's assessment and she did not feel there was any back up support from Adult Social Care. She has contacted them but keeps getting admin staff and no one to answer her questions. She has since found out that there is a lack of social workers available. She was sent a leaflet last year about Community Access & Re-enablement (CARS) which is for people over 60 to re-learn to look after themselves. She feels this is dreadful as it doesn't take into account the people with dementia/Alzheimers cannot re-learn. She asks that carers could be given 10/15 mins as part of the assessment to talk and prepare the cared for person for the assessment interview. Her mum was confused and didn't know what was going on. She also couldn't answer any questions because of her Alzheimer's. The assessment process is too long (2 hrs) and is very stressful both on the carer and the cared for person. The form also needs to be shorter as it is too long.

- Lady has a condition which affects her brain. She also has a young child. Her parents have been her main carers. Four years ago she had an assessment with a social worker who said that a flat would be found for her to live independently with support. A financial assessment was also done and it was said that being a single parent she would not have to pay for her support. She has waited up to a year and still heard nothing from Adult Social Care. She contacted the Carers Centre who rang Adult Social Care to find out that the social worker had moved departments and not told them. They also had no record of the lady's assessment. With the help of the Carers Centre another assessment was arranged - a complaint was lodged but the reply wasn't helpful. The Carers Centre again help along with SHINE arranged another assessment (and they attended the interview with her to explain what her condition was and how it affected her). Another social worker took over after the original one went on maternity leave, so nothing happened for 3 months. Client is not hopeful that things will be resolved soon.
- Gentleman's wife has Parkinson's -They had the house adapted - floor lift, 2 hoists (upstairs and downstairs) and a ramp outside. After her assessment her care plan was reduced by £400. They asked for a reassessment and were told that the original figure was wrong. It was confirmed that the money would be backdated but they are still waiting for this money. They were not told after the assessment that the care plan was being reduced and they had to chase adult social care to get a reassessment. His own health has deteriorated. He has just spent 2 days in the hospital for exploratory surgery. He has no energy and is tired all the time. He was assessed at the same time as his wife and had his care plan reduced from £675 per month to £147. After asking for a reassessment his hours were increased from 3.5 hrs to 7.5 hrs but again the money has not been backdated as promised. He feels very annoyed as the social worker made

comments about his being ok and had nothing wrong with him on his visit.

- She is very unhappy about the lack of information and guidance around procedures and reviews (concerning the care of her mother). She is her mother's carer. She says she often receives a phone call to say they are coming for one type of meeting, then it turns out to be for something else. You are not told that you can have (and might need) an advocate there - she recommends Disability Sheffield, or a friend who is very astute and can take accurate notes. A recent meeting turned out to be a review of her healthcare needs, there was a Nurse from the PCT, and RMN, A CPN and an Age UK advocate. She felt that the Nurse's attitude was aggressive, and she felt under threat of them taking her mum into care, because they kept saying to her "Well if you can't cope..." She felt that they wanted to make all the decisions for her and her mum. They didn't have their own advocate present because she wasn't told that it was going to be a 'cost-cutting' meeting. As a result of the meeting, her mum's funding was cut by half, and she has lost funding for her mum's P.A. She felt bullied and has lost any confidence to now ring for help, because she is terrified her mum will be put in care, despite the fact that she is capable of caring for her herself, given the right support. They are appealing against decision with the help of Disability Sheffield. They are unhappy that the DST (Decision Support Tool) which they felt took too long to be sent to them, and it wasn't detailed enough - significant illnesses were missed out, and it was based purely on physical ill-health, with no professional psychiatric input. (Her mother has late-stage Alzheimer's). A "short report" was later requested from a CPN. Although they are now challenging the report, they are unhappy because they were not told clearly before that if you ask for a new DST and are successful, the funding will not be backdated.
- Direct payment for care should not be a 'one size fits all' way of receiving care. Many people who require care cannot manage direct payments and all its implications. Changes client would like - care provided by health service (NHS) and the local authority needs to be as one (joined up). Care should always been in place when someone is discharged from hospital. Carer has cared for their disabled child for the last 30 years and is now elderly. They have requested a carer's assessment 12 months ago, and have not had one.
- Person and their partner are the main carers for mother in law, in her 90's. They have been looking after her since Nov 2011, when she moved to live with them. At present mother in law is in hospital after having a fall and carers feel they can no longer look after her on their own. They don't want to put her in a home but feel they need extra help to care for her. She has never had a care package in place as they have done all the caring. The hospital has not mentioned anything about a care package/assessment and they are wondering is this something they should do but have no idea how to go about it. They were given information to ring the Carers Centre who can support and provide information on adult social care process.

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